

NEGATIVE IMPACTS STEMMING FROM THE LACK OF SEXUAL EDUCATION IN AUTISTIC PEOPLE ASSIGNED FEMALE AT BIRTH: AN EXPLANATORY MIXED METHOD STUDY

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ABSTRACT: Sexual education has been deficient in serving the needs of mainstream and marginalized populations, rife with misinformation about sexual health. This negatively impacts everyone, especially marginalized groups such as autistic women and nonbinary people who are more likely to be sexually assaulted than the general population. Present and past stigma towards autistic people has led to insufficient sexual health education, as it ignores the specific needs and accommodations necessary for this population. This study uses a mixed methods explanatory design to gather quantitative data through surveys, which will be used to create relevant questions for the qualitative data stage. The qualitative stage involves interviewing autistic women and nonbinary people about their sexual education experiences and what they want for the future of disability informed sexual education. This study prides itself on its commitment to community involvement throughout the entire process as autistic people, (especially women and nonbinary people), have been left out of the programming and research that is written about them. The commitment to autistic participant involvement is novel and will improve the quality of intervention and sexual health outcomes in the future.

Identity & Intersectionality: Gender, Sex, and Autism

There are an estimated 5.5 million adults who identify as autistic in the United States, around 2.2% of the population (CDC, 2020). As stated previously, autistic is used in place of “person with autism” due to many self-advocates in the community preferring this naming convention (Brown, 2011). Botha et. al., (2021), assert that the distinction is linguistic in nature, and the combination of person with (noun) is common in denoting the existence of an illness. “Other nouns (or noun phrases) that may be substituted in the second position for “autism” include those such as “cancer”, “liver disease”, “a headache”, “Covid-19”, etc.” (Botha et. al., 2021). Language shapes how people understand autism, advocates for identity first language assert that autism is not an illness and should not be referred to as such (Botha et. al., 2021). Person-first language can be interpreted as pathologizing a part of an

individual’s identity, implying that autism can be cured or “overcome,” which is stigmatizing and untrue.

Autism is a lifelong developmental disability with a myriad of symptoms that present on a spectrum (CDC, 2021). These include sensory processing issues, differences in communication and socialization, or difficulties with activities of daily living (Autistic Self Advocacy Network). Additionally, it is important to note that while some autistic people have intellectual disabilities, that is not the case for the entire population (Baines et. al., 2019). This paper’s focus will be specifically placed on investigating the sexual education experiences of English-speaking autistic people who were AFAB. AFAB is used to describe people assigned or assumed female at birth instead of women because gender roles and ideals are socially constructed. This distinction becomes increasingly important later in the study when discussing gender identity. Social ideas of gender impact all aspects of life,

including the diagnostic tools and processes used for autism testing. AFAB autistic people are underdiagnosed in comparison to their assigned male at birth (AMAB) counterparts (Kriser & White, 2015). While exact causes of this discrepancy are unknown, Geelhand et al. 2019's study on gender and perceptions of autism symptoms posit:

That (in) reaching adolescence, girls become more likely to experience harsh social sanctions when displaying atypical behaviors such as social withdrawal than during childhood as these will now contrast with the gender- and age-specific expectations of more sophisticated social skills. (para. 10).

People who are AFAB are socialized differently from early childhood on and are expected to be more socially adept than their AMAB counterparts. The diagnostic criteria for autism was created with AMAB autistic experiences in mind (Rynkiewicz et al., 2019). The discrepancy in presentations of autism between people AFAB, in comparison to the diagnostic criteria created for AMAB autistic people, results in a high rate of mis/undiagnosed AFAB people (Kriser & White, 2015). People socialized as women and girls are encouraged to put more emphasis on social ties than those socialized as men and boys. This has led to a lower percentage of AFAB people being diagnosed with autism than AMAB people (Rynkiewicz et al., 2019). Current research is limited in describing the ways that sexual education can be made more accessible to AFAB autistic people. Therefore, studying an underserved population is both innovative and important for improving sexual health outcomes.

Negative Sexual Health Outcomes

An important theme was discovered in the literature review process regarding AFAB autistic people and negative sexual health outcomes. Hannah & Stagg's 2016 study found that autistic AFAB people were more likely to have had sexual experiences than autistic

AMAB people and were comparable to their non-autistic AFAB peers. Autistic AFAB people are also at increased risk of adverse sexual experiences compared to their AMAB autistic counterparts (Hannah & Stagg, 2016). Autistic AFAB people were found more likely to agree to an unwanted sexual experience than non-autistic AFAB people and autistic AMAB people (Hannah & Stagg, 2016). Autistic AFAB people were also significantly more likely to be the victim of unwanted sexual behaviors than non-autistic AFAB and autistic people AMAB (Hannah & Stagg, 2016). Brown-Lavoie et al., (2014) found that 78% of autistic participants reported one or more sexual victimization experiences, in comparison to 47.4 % in the control group, which emphasizes the need for targeted sex education in this population. Autistic participants were more likely to experience sexual victimization, up to 2.4% more likely to experience rape, and almost three times more likely to have had an unwanted sexual experience (Brown-Lavoie et. al., 2014). This could stem from lack of understanding of consent, difficulty with reading social cues, as well as low self-efficacy in asserting boundaries. As discussed previously, some autistic people have intellectual disabilities. People with intellectual disabilities have been found to have less sexual experiences than their non- intellectually disabled counterparts. However, if sexually active, they are more likely to participate in unsafe sexual practices, resulting in higher rates of STIs (Baines et. al., 2018). Baines et al. (2018) hypothesize that this discrepancy could be a result of sexual health information withheld from intellectually and developmentally disabled people. The data showcased above illustrates the essential need to study the needs and vulnerabilities of AFAB autistic people. Autistic AFAB people deserve to have healthy, fulfilling and safe sex lives. Sex education with their needs in mind must be created to stop this endemic rate of sexual violence.

Barriers to Including Autistic People in Sexual Education and Research

Traditional sex education in schooling is not accessible or inclusive of autistic people's needs. Pecora et al. (2019) demonstrated that autistic participants did not report perceiving that they needed more sex education than their non-autistic peers. However, they also found there were great discrepancies between autistic and non-autistic young adults in terms of sexual knowledge, as well experiences with sex and sex education. The data showed that autistic participants had significantly lower scores in the sexual awareness questionnaire in comparison to their non- autistic counterparts. The authors posit that the reason for the discrepancy is because sexual education is lacking for both autistic and non-autistic students (Hannah & Stagg, 2016). However, non-autistic students may supplement their lack of effective sex education through social discussions (Pecora et. al., 2019). Autistic people are more likely to have difficulty socializing, so this may explain their lag in sexual awareness (Hannah & Stagg, 2016). This research paper will include the perspectives of autistic people and what they want to see in future sexual education. While it may seem intuitive to ask the people who are receiving services what they need, autistic people specifically have been left out of discourse about their own healthcare. This paper seeks to start the process of introducing autistic perspectives into academia and the existing evidence base.

Like many marginalized populations, academia and scientific literature is often written about, and not by autistic people. This has led to paternalistic and inaccurate portrayals and views of autistic people among clinicians, researchers, educators, parents, and the general public (Nicoladis et. al., 2012). It has also impacted the kind of information and education available to autistic people. Many autistic people are just as interested in sex as the general population, and without input from those communities directly,

there is a high probability for error or ineffective programming to be created (Hannah & Stagg, 2016). Included below is an excerpt from Elle Loughran, an autistic woman in academia, on her experience of reading studies about autistic people:

Reading autism research as an autistic person can feel like being treated as an alien. For example, consider a 2019 paper that stated: "This finding reinforces other work which shows that autistic people can have, maintain, and value close romantic relationships and friendships." Imagine how bizarre it would be to read that about yourself. Autistic people are not aliens with whom scientists cannot communicate. We are right here. We are reading what you have to say, and that communication can go both ways (Loughran, 2020, para. 3).

This study seeks to include autistic people themselves in conversations that are relevant to their health and wellbeing. Qualitative research that includes the perspectives of the participants studied can start the process of including autistic voices in academic research.

Research Approach and Hypothesis

Targeted comprehensive sexual education intervention in young AFAB autistic people will result in better sexual health outcomes. The quantitative section will conduct a survey to gather data on the following questions: Is there a correlation between lower reported satisfaction with sexual education and experiences of sexual violence? Is there a correlation between lower sex education satisfaction and lower self-efficacy in sexual situations? This study hypothesizes lower sex education satisfaction scores will correlate with higher sexual victimization experience scores, and lower sexual self-efficacy scores.

The qualitative portion of the study will be interviews of adolescent AFAB students. The following themes will be explored: How can sexual education be made more accessible for AFAB autistic people? Will including autistic

people in curriculum planning increase the efficacy of said program? Other questions will be formulated after reviewing the quantitative data and discussing with a group of autistic stakeholders. Adding autistic people into the planning process of sexual education programs increases their efficacy. It also allows for greater transparency and accountability for the researchers to the autistic community. Social differences impact the way autistic people understand sexual health, therefore future interventions must address this in their designs. Making sexual education more accessible for autistic people should include more information about communicating consent, gender and sexual orientation conversations and building self-efficacy. This research proposal is directly influenced by principles of community based participatory research because of its commitment to community involvement, as well as the focus on an understudied population: AFAB autistic people (Nicoladis et. al., 2012). Therefore, the dedication to include autistic people throughout the entire study is of utmost importance.

Methods

Study Design

This study is a mixed methods explanatory sequential study. Mixed methods explanatory research involves both quantitative and qualitative data to investigate a research question (Creswell, 2018). This specific design was chosen because of the synthesis of qualitative and quantitative data, allowing for numerical data to be presented in context with personal testimony from autistic people. Mixed method explanatory design is useful in this study for creating a holistic picture of the barriers in obtaining effective sexual health education in AFAB autistic populations. This design is also effective as it fills a gap in numerical data regarding AFAB autistic people's experiences of sexual education. The qualitative data is especially important in regard to the study's commitment to prioritizing the autistic community's perspectives throughout.

The quantitative surveys will be cross-sectional, due to the large sample size. Cross sectional studies collect data at one point in time and are effective in reaching a large number of participants, especially in studies with less financial resources (Creswell, 2018). The study expects to find a connection between low sexual education experience satisfaction, and high scores on the Sexual Experience survey: Victimization Edition and lower sexual self-efficacy scores respectively.

The qualitative portion will consist of one-hour long interviews, with breaks allowed at any time to ensure accessibility. These interviews add important context and human perspective to the quantitative data, which is consistent with the goals of the study to focus on including autistic participant's viewpoints and positions throughout. The design is influenced by the emancipatory and community-based research approaches, in which the participants are considered stakeholders throughout the research process, from the question formation, to the data analysis, to the overall significance and future directions. While past studies that involve autistic people in emancipatory designs are rare, there is push from members of the autistic community to include their perspectives throughout the entire research process (Kourti & MacLeod, 2019; Nicoladis et.al., 2011).

Phase 1: Quantitative Surveys

Phase 1: Participant Recruitment and Sampling

For phase one, a cross sectional quantitative survey will be distributed to collect a wide range of perspectives of autistic people about their participation in sexual education. This study focuses on English speaking Autistic people who identify as AFAB, from ages 18 to 24. The participants will be recruited via convenience sampling on reddit, Instagram, Tumblr, and other social media platforms, utilizing boards specific to autism. Convenience sampling will be used because of its cost and ease of access.

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For the survey portion, the objective is to get the most responses so there is a wide variety of experiences represented. There will be up to 1000 participants allowed.

No formal diagnosis is needed to participate in the study. Autism diagnoses are difficult to seek out for a few reasons. First, the diagnostic process can be expensive, especially when it is not covered by insurance. Second, this study is focused on AFAB autistic people who are often un/misdiagnosed, and requiring a formal diagnosis is not inclusive to this population's presentation of autism (Rynkiewicz et. al., 2019). Each participant is screened using both the AQ test and the RAADS-R (Ritivo et. al., 2011; Baron-Cohen et. al., 2001). If the participants meet the threshold for one or both of the tests, they are eligible for the study. AQ is the primary autism testing method; however, because of the narrow demographic it was based on (young white cisgender boys), it often does not detect autism symptoms from people with intersecting identities (Rynkiewicz et. al., 2019). Nonetheless, the AQ is commonly used in autism research, so it will be used to allow this research to be in conversation with other studies. Therefore, the RAADS-R, which was created to assess people who are commonly missed in the AQ, will be administered alongside the AQ. The threshold score for the AQ is 26, and RAADS-R is 65, anyone with scores above them in either test is eligible and considered on the spectrum for this study. A list of resources for diagnosis and psychoeducation about autism will be provided after the test is finished if someone scores within the threshold.

Phase 1: Materials and Methods of Data Collection

This survey is cross-sectional in nature. The cross-sectional data will represent a relationship between AFAB autistic people's sexual victimization scores, self-efficacy scores, and sexual education satisfaction scores. The main survey will be a combination of previous tools, tailored for this study's population. The

researchers did not find an applicable survey for this study's population, so existing tools were compiled into a new questionnaire. It will include four parts: demographic data, sexual education experiences satisfaction, sexual health self-efficacy, and experiences of sexual violence. The tools used to create a new survey include the revised Sexual Experience Questionnaire: Victimization Edition, Sexual Self-Efficacy Scale and supplementary questions written by the researchers asking directly about participant's satisfaction with their sexual education experiences (Brown-Lavoie et.al., 2014). Demographic data such as race, ethnicity, sexual orientation, age of first sexual experience, and gender identity will be recorded as well. The surveys (aside from the demographic questionnaire) will be measured on a Likert scale (strongly disagree, disagree, neither agree or disagree, agree, or strongly agree). If the surveys used different scales to measure their data, they will be modified for a Likert scale for use in this study. The validity and reliability of the surveys will be measured prior to the start of sending out surveys.

Phase 1: Operationalization and Measurement

AFAB person is defined as someone who identifies as assigned female at birth (Kourti & Macleod, 2019). Gender identity is defined as one's inner experience and outward expression of gender, including cultural expectations, not to be confused with biological sex (Planned Parenthood). Sex is defined as a multifaceted biological construct involving anatomy, genes, hormones and physiology that when combined informs how people are labeled (Johnson et. al., 2007). An autistic person is defined as someone with an AQ score over 26, and/or a score above 65 for RAADS-R (Ritivo et. al., 2011; Baron-Cohen et. al., 2001). Because of financial, social and institutional barriers to diagnosis, a medical diagnosis is not required to be considered autistic for this study (Rynkiewicz et. al., 2019). Sexual education is defined as a program or

curricula designed to teach people about sexual practices. This includes comprehensive sexual education that focuses on STI and unplanned pregnancy prevention, consent, and self-efficacy skills, as well as more limited or abstinence only sexual education (Advocates For Youth, 2014). Inclusion/Inclusive practices in education are defined by curriculum and practices that ensure the participant's access and benefit to said education (Campbell, 2016). Sexual health efficacy is defined as a participant's confidence in applying knowledge of sexual health to their sexual experiences, including knowledge and ability to advocate for one's needs (Brown-Lavoie et.al., 2014). Sexual victimization is measured by Sexual Victimization (SES V) survey as any experience of unwanted sexual contact, and any sexual experience without consent (including rape, sexual assault, harassment, coercion, intimate partner violence (Brown-Lavoie et. al., 2014).

Phase 1: Analysis

The unit of analysis for the quantitative stage of data is individuals. Descriptive statistics such as frequency, mean, median and mode will be analyzed. Multivariate analysis will be used find patterns within the data among age, race, sexual orientation, and gender identity. Odds ratios will be conducted to determine the associations between satisfaction with sexual education and scores on the sexual violence survey, and sexual self-efficacy scores respectively.

Phase 2: Qualitative Semi Structured Interviews

Phase 2: Participant Recruitment and Sampling.

The last question on the preliminary survey from Phase 1 will ask participants if they wish to participate in an upcoming qualitative structured interview. Participants who wish to enroll will indicate it in their survey, along with email and phone numbers for the researchers to contact them with more information for the interview. There will be a total of fifteen semi- structured qualitative interviews, and the

participants will be demographically selected to attempt to represent the general population as much as possible. Participants who experienced high sexual violence scores or have lower sexual health self-efficacy scores will be specifically valuable to this study; therefore, recruitment will prioritize those who are a part of those aforementioned categories.

Phase 2: Materials and Methods of Data Collection

Semi- structured qualitative interviews will be administered over online meeting services (such as Microsoft Teams or Zoom). In a similar study utilizing community based participatory research principles with autistic people, online interviews were used. Online interviews allow for participants to participate regardless of geographic location. This mode of interview was "deemed appropriate as electronic communication is often cited by autistic adults as a preferred way to communicate due to its relative simplicity and lack of social pressure" (Kourti & MacLeod, 2019). Therefore, interviews will be administered online. These semi- structured interviews will consist of open-ended questions so that participants will have the opportunity to add their perspectives and guide the interview as they see fit. To emphasize this research's commitment to inclusion and autistic empowerment, the authors will work with autistic people themselves to create questions based on their interpretation of the quantitative data. Because this is an explanatory sequential mixed methods design, the questions will be informed by the survey answers from the previous phase. This is effective as it allows a wide population of autistic people to be influencing the process. Questions about the quality of sexual education participants received will be asked. These will include questions about their sexual education experience's applicability in their current sexual behaviors, whether or not they felt included in sex education settings, and what they feel could improve to make sexual education more accessible to autistic people. Qualitative research was chosen for this phase to allow

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autistic people to explain their experiences in their own words.

Phase 2: Analysis

The qualitative data from the fifteen semi-structured interviews will be coded using Braun and Clarke's 2006 six thematic analysis phases (Maguire & Delahunt, 2017). This was chosen because of its usefulness for identifying patterns in themes in qualitative data. The steps are as follows: First, familiarizing oneself with the data, second, generating initial codes, third, looking for themes, fourth, reviewing themes, fifth creating definitions for the themes, and sixth, creating a write up for the themes. The codes that the researcher expects to find within the research are inclusion within sexual education classes, experiences of sexual victimization, communication differences, and lack of self-efficacy, as well as confusion with sexual education curriculum.

Ethics

The main ethical considerations include the sensitivity of the subject of sexuality and its intersection with the autistic AFAB population studied. Accommodations and explanations will be given at any time during the study to ensure the safety and protection of the population studied. This study is seeking approval from the University of Washington's Institutional Review Board. Informed consent forms will be available in plain language, with options for auditory format for accessibility purposes. Participants will be encouraged to ask questions if there were concepts they did not understand, and the researchers will provide alternate explanations of questions to ensure accessibility and inclusivity. Participants will also be reminded of their right to discontinue participation in the study at any time and for any reason throughout the survey and/or interview process. Participants in the quantitative survey have the opportunity to be both anonymous and have their information kept confidential. Those who choose to answer the last question are prompted to include their email or phone

number so that they can be contacted about the upcoming qualitative interview process. Their data will be kept confidential, but it will not be able to be anonymous.

Discussion

Significance

Many people within the autistic and disability rights communities' education have called for disability informed and inclusive sexual education (Yee, 2021; Brown-Lavoie et. al., 2014). This study responds to the call and helps to fill the gap in the knowledge of autistic AFAB people experiences of sexual education. The design itself is innovative, as it prioritizes disability inclusion in academia, by empowering autistic people to be a part of the research and planning of sexual education programs. Research on AFAB autistic people is sparse in general, and there are currently no published studies focusing specifically on autistic AFAB people's experiences of sexual education. The findings of this research could also help increase awareness of autistic people's high rates of sexual victimization. Sexual assault survivors often experience suicidal ideation, and autistic people have higher suicide rates than the general population (Kölves et. al., 2021). This research and its applications can reduce lives lost to suicide, as well as lower rates of sexual violence and PTSD. This data can be used to create new, effective sexual healthcare programs for AFAB autistic people. Improving self-efficacy and quality of life for people on the autism spectrum is a worthy goal to work towards. The study data will be especially useful as it is designed with and for autistic people. Possible improved health outcomes could be lower rates of STIs and sexual victimization, and higher self-efficacy within sexual experiences.

Limitations

Due to resource limitations, this study used convenience sampling and therefore there is also potential for lack of generalizability. The cross-sectional design also does not lend itself to conclusions of causality; therefore, there is a

need for causal studies in the future to correct this. This study can be used as a base of knowledge for studies with greater resources to continue research with a randomized control trial. While qualitative studies are effective for including perspectives of community members, they are not representative of everyone who identifies as autistic. The data will be representative of AFAB autistic young adults (18-24) and may not be applicable to younger or older age ranges. On the note of reflexivity, the primary researcher is employed at a program that supports autistic and other neurodivergent college students, and their research and motives are influenced by this experience. The researcher is also a member of the disability rights movement, and therefore their perspectives are influenced by this philosophy.

Future Directions

While this study did its best to be accessible with intersectionality in mind, there are opportunities for further research studying various subgroups of autistic people. Of particular note is studying autistic people who are nonverbal, and autistic people with intellectual disabilities. Many studies have left people who are nonverbal and people with intellectual disabilities out of their research, and there must be concerted effort to rectify this. Future studies should also focus on gender non-conforming and trans autistic people's perspectives on sexual education. Studies focusing on other underdiagnosed/under-studied populations such as autistic people of color or autistic people in the global south are needed for further depth of understanding. Further studies could also be focused on the relationship between late diagnosis and experiences of sexual violence among AFAB people. Other future directions include randomized control trials that seek to determine the cause of higher sexual violence rates among autistic populations. This is particularly important because of the quality of life and suicide prevention applications. This study can also help lay a foundation for inclusive curriculum and teaching approaches. Gaining

information on what autistic people need from their sexual education is the first step to creating curriculum that meets those requirements.

Future Research

This preliminary research is a base for future studies. One of the most urgent areas for future study in autistic populations is an investigation of associations between gender dysphoria scores and lower sex education satisfaction. Sex education is lacking in addressing queer and trans healthcare, even in comprehensive sexual education programs. This is especially troubling for autistic populations, as there is a higher percentage of autistic people who identify as LGBT. According to George & Stokes's 2018 study, autistic participants were more likely to experience gender dysphoria than their non- autistic counterparts. But unlike what was predicted, AFAB autistic participants only differed from AMAB autistic participants on the subjective scale of gender dysphoria. Higher gender dysphoria scores were correlated to AQ communication skills and AQ social skills. This may indicate that social and communicative skill differences in autistic people relate to a higher proportion of gender dysphoria symptoms. A large population-based study from Sweden also described higher rates of non-cis/heteronormativity among autistic people in comparison to non-autistic people. They suggest that this may be because autistic people are less interested in social norms, and therefore more open to difference in sexual identity (Rudolph et al., 2017). Inaccessible sexual education combined with cisnormative/heteronormative curricula further disempowers the sexual health of autistic people with intersecting identities. Another point of note was the intersection of ableism and transphobia, where some participants described others invalidating their identity because of their disability. One participant from the study stated, "They viewed it as an obsession, but it's really not the same thing and I don't know how they thought that ' (Theme 4: Bias and Harassment). This participant is describing their identity

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being questioned because of their disability. Sexual education that does not consider the unique needs of the LGBT community leaves people in danger of unsafe sexual practices. Gender diverse and LGBT inclusive sexual education is needed for everyone, especially autistic populations. Further studies may use the knowledge gained through this study to build trans and autistic specific sexual education.

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